

The Roy Castle Lung Cancer Foundation (RCLCF)
Third Annual National Lung Cancer Patient Meeting
Liverpool, Wednesday 10th September 2003.

Meeting Summary

On Wednesday 10th September, 70 representatives from the 24 Roy Castle Lung Cancer Patient Support Groups across the UK, met at the RCLCF Centre in Liverpool. This was the third year such a meeting had taken place.

There were four key objectives to this meeting :

1. To educate / inform meeting delegates (patients/carers) on relevant lung cancer issues
 2. To inform delegates on the RCLCF's Patient Care work, ensuring a continuing patient focus.
 3. To encourage patients/carers to become more involved in advocating on lung cancer issues.
 4. To collate patient/carer opinions on aspects of lung cancer and its care.
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Objectives

1. To educate / inform meeting delegates (patients/carers) on relevant lung cancer issues

This was achieved through formal lecture presentation and panel discussion and also informal networking between delegates outwith the lecture venue. In particular, three invited experts gave the following stimulating presentations:

- The Practicalities of Achieving Best Practice Lung Cancer Patient Care
Dr Mick Peake
(Consultant Respiratory Physician and Lead Lung Cancer Clinician, England)
- The Evolving Role of the Lung Cancer Nurse Specialist
Mr Andrew Wilson
(Chairman, The National Lung Cancer Forum for Nurses)
- Improving Lung Cancer Outcomes – What does the future hold? (new developments, research etc.)
Dr Heather Anderson
(Consultant Medical Oncologist)

2. To inform delegates on the RCLCF's Patient Care work, ensuring a continuing patient focus.

All of the patient/carer delegates were members of one of the RCLCF's 24 monthly Lung Cancer Patient Support Groups. As such, they were already aware of many aspects of the Foundation's work. Jennifer Dickson (Patient Network Manager,

RCLCF) gave a formal update on the Lung Cancer Patient Support Network and its future direction. Dr Jesme Baird (Director of Patient Care, RCLCF) reported on the Lung Cancer Awareness Month campaign, November 2002 (a joint campaign with Macmillan Cancer Relief) and activities planned for the November 2003 campaign.

3. To encourage patients/carers to become more involved in advocating on lung cancer issues.

Since January 2003, the RCLCF has funded a program of involving patients/carers, in a variety of ways, in working towards the improvement of lung cancer patient outcomes. Lynne Robertson (Patient Involvement Co-ordinator, RCLCF) reported on the training program, established to ensure advocates are equipped to provide media comment and to become patient representatives on key NHS committees and policy setting bodies. Delegates were informed about the practical ways in which they could contribute to improving lung cancer outcomes and encouraged to participate.

Patients/carers can make a difference by :

1. Working with the media:
 - Providing case histories - “telling their story”
 - Writing to local newspapers (“letter to the editor” section)
2. Raising lung cancer awareness amongst the general public
 - Distributing campaign materials
 - Putting up posters and displays
3. Political campaigning
 - Write to their elected representatives, raising awareness of lung cancer and key issues (MPs, MSPs, MEPs, AMs)
4. Impact directly on the delivery of the clinical service by:
 - Being a “patient/user” representative on key health service committees
 - Inputting their opinions into focus groups and surveys on the views and experiences of service users

The RCLCF will support patients/carers who wish to help in any of the above ways.

4. To collate patient/carer opinions on aspects of lung cancer and its care.

During the meeting, we had the opportunity to make use of key-pad voting technology and ask patient/carers about their experience and opinions on a number of lung cancer issues. The following is a summary of the characteristics of the responders and the responses received.

4.1 Patient/carer characteristics

- Number of responders
 - Between 55 and 61 patient / carer responders
- Age distribution
 - Less than 45 years old 7%
 - Between 46-55 years old 23%
 - Between 56-65 years old 39%
 - Between 66-75 years old 20%
 - More than 76 years old 11%

- Sex distribution
 - Male 26 Female 35

- Lung cancer experience
 - Current Patient 35%
 - Previous Patient 22%
 - Relative or Friend 43%

- Treatment experience (as patient or carer)
 - Chemotherapy 42%
 - Radiotherapy 44%
 - Surgery 50%

- All of the patients and carers who took part were members of a Roy Castle Lung Cancer Patient Support Group and as such have monthly access to a Lung Cancer Nurse and to Information and Support Services. As is further evidenced by the treatment experience above and by the mere fact that they were willing to spend time to attend the Meeting, these are **not “typical” of the general lung cancer patient experience.** They would be classed as “high information seekers” and, as a group, in a better prognostic category, when compared with the disease as a whole.

4.2 Patient/carers experiences

(carers were asked to comment on the experience of their loved one)

1a. How long did it take from you experiencing your first symptom to being diagnosed with lung cancer?

- | | |
|-----------------------------|------------|
| a) Didn't have any symptoms | 27% |
| b) <1month | 24% |
| c) 1month | 0% |
| d) 2months | 12% |
| e) 3months | 5% |
| f) 4months | 2% |
| g) 5months | 2% |
| h) >5months | 27% |

1b. For those who waited longer than 2 months, was the delay due to patient issues (eg. not seeking medical help) or professionals issues (delays in the health system, not referred for tests etc..)

- | | |
|---|------------|
| a) Patient Issues | 38% |
| b) Professional/Health System Issues | 63% |

2. In general, how good are/were your doctor and treatment team at explaining your treatment options with you throughout your care?

- | | |
|--------------|-----|
| a) Excellent | 55% |
| b) Good | 14% |
| c) Average | 23% |
| d) Poor | 9% |

3. If and when you had any problems or concerns during your lung cancer care, how easy was it for you to obtain appropriate advice when you needed it?
- | | |
|-----------------------------|-----------|
| a) Very easy | 47% |
| b) Moderately easy | 29% |
| c) Difficult | 7% |
| d) Very difficult | 4% |
| e) Impossible | 9% |
| f) Didn't have any problems | 4% |
- 4a. Were you referred to a lung cancer support nurse on diagnosis?
- | | |
|---------------|------------|
| a) Yes | 58% |
| b) No | 42% |
- 4b. If you were referred to a lung cancer support nurse on diagnosis, how important was it to you?
- | | |
|---------------------|------------|
| a) Extremely | 88% |
| b) Very | 12% |
| c) Not very | 0% |
| d) Not at all | 0% |
- 5a. When you were discharged home from hospital or completed treatment, were you referred to anyone for follow up at home (eg. District Nurse, Community Nurse Specialist etc...)
- | | |
|--------------|------------|
| a) Yes | 35% |
| b) No | 65% |
- 5b. If you were referred to anyone for home follow up, how important was this?
- | | |
|---------------------|------------|
| a) Extremely | 81% |
| b) Very | 12% |
| c) Not very | 5% |
| d) Not at all | 2% |
- 6a. In the past have you challenged your doctor?
- | | |
|--------------|------------|
| a) Yes | 22% |
| b) No | 78% |
- 6b. Having listened to the experts at this meeting and having found out more about lung cancer service provision, would you challenge your doctor now?
- | | |
|---------------|------------|
| a) Yes | 96% |
| b) No | 4% |
7. How did you find out about the information and support services provided by the Roy Castle Lung Cancer Foundation?
- | | |
|----------------------------|------------|
| a) Nurse told me | 59% |
| b) Doctor told me | 7% |
| c) Friend/relative told me | 9% |
| d) Poster | 5% |
| e) Booklet | 9% |
| f) Internet | 4% |
| g) Other | 7% |

4.3 Patient/carer opinions

1. Under what circumstances would you agree to take part in a clinical trial?

- | | |
|--|-----|
| a) Always – there's not enough research | 50% |
| b) Even if it doesn't help me, it might help others | 34% |
| c) If I thought that I might be the lucky one | 6% |
| d) Only if there was a good chance it would help me | 10% |
| e) Never – patients in clinical trials are "guinea pigs" | 0% |

2. Would you travel two hours or more each way, to be treated by someone more specialist in lung cancer?

- | | |
|---------------|------------|
| a) Yes | 95% |
| b) No | 5% |

3. Lung cancer receives as much media attention as other common cancers and diseases

- | | |
|--------------------|------------|
| a) Agree | 3% |
| b) Disagree | 93% |
| c) Don't know | 3% |

4. You or the patient for whom you are caring/cared for, have gone to the hospital for a chest x-ray because there is a chance you could have lung cancer. Would you prefer:

- | | |
|---|------------|
| a) To go back to your GP to receive the results, then be referred? | 17% |
| b) If the test suggests there might be cancer, to be sent straight to see a hospital based specialist? | 83% |

5. You or the patient for whom you are caring/cared for, have just been diagnosed with lung cancer at the hospital, Would you prefer:

- | | |
|--|------------|
| a) To receive some tests to help determine you treatment on the same day? | 87% |
| b) To leave some time for it to sink in, before any test are arranged? | 13% |

6. Upon being given a diagnosis of lung cancer, would you or the patient for whom you are caring/cared for, prefer:

- | | |
|---|------------|
| a) To receive information on all possible tests and treatment options at this point? | 74% |
| b) To receive detailed information specific to you and your needs, as and when you need it? | 26% |

7. You have been given a diagnosis of lung cancer and have received information on possible tests and treatment options. Who would you prefer to discuss your general questions with?

- | | |
|--------------------------------|------------|
| a) Your GP | 2% |
| b) Hospital Doctor | 64% |
| c) Lung Cancer Nurse | 33% |
| d) Cancer Support Organisation | 2% |

8. From the following list, which one is most important to you?

- | | |
|---|-----|
| a) To see the same doctor every time I go to the clinic. | 62% |
| b) Dedicated breathlessness services, to help me breathe better | 5% |
| c) A Lung Cancer Nurse throughout my treatment | 22% |
| d) Ability to park my car at the hospital | 7% |
| e) Every time I attend the clinic, to wait half an hour or less | 4% |

We will present these opinions/experiences at key lung cancer meetings and with relevant health professionals, to ensure that seeking lung cancer patient/carer opinion is encouraged and that changes to service delivery, reflect such views.

Meeting Feedback – Evaluation from Patients and Carers

1. How did you find the speakers?

Excellent	55%
Good	40%
Average	5%
Poor	0%

2. Any topics not discussed?

Yes	20%
No	80%

(Yes, included: more specific information about the disease, spread & treatment of this, how to improve post-operative domiciliary care, more on *Iressa*, and other new therapies).

3. Do you feel you had the opportunity to contribute to the discussion?

Yes	92.5%
No	7.5%

4. How worthwhile did you find the interactive keypad voting?

Very	87.5%
Fairly	12.5%
Not very	0%
Not at all	0%

5. On the overall meeting, are there any areas which you felt could have been improved upon?

Yes	15%
No	85%

(Yes, included: more time (main issue). Also noted, was some difficulty in hearing the chairman speak and a slight overlap in information from speakers)

6. Overall, how did you find the meeting?

Excellent	72.5%
Good	20%
Average	7.5%
Poor	0%

Acknowledgement

We would like to thank *Astra Zeneca*, *Aventis* and *Pierre Fabre* for their support of this meeting. Without their help, it would not have been possible to bring these lung cancer patients and carers together.

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